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ABSTRACT

This paper reports on several projects conducted in Georgia over the past 2 years that move the development of respite care services toward the goal of becoming a "cooperative, collaborative, and coordinated" effort. An overview of respite care in Georgia is provided as well as a summary of strategies used to provide such care. Emerging principles, directions, issues, and guidelines are identified, and the present provision of services primarily by area-based developmental services programs is noted. The networking and cooperative strategies that have occurred at three levels (county, metropolitan, and statewide) are summarized, and 10 guiding principles are described. They include respite care as a community wide need, the involvement of families and caregivers in the planning and delivery of services, the development of community ownership of respite needs services, and respite care as providing benefits for everyone involved. A few pointers for others are offered; they include the impossibility of forcing networking, the importance of family involvement for maintaining common ground, and the value of starting small. Also included is a summary of results of a 1988 survey of 30 Georgia program offices; insufficient funds was the most frequently cited problem and the provision of services to clients with severe medical problems was cited as the most difficult need to meet. (DB)

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Cooperative Approaches to Respite Planning and Development
1990 AAMR Conference Presentation

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At the first state-wide conference in Georgia on respite care, Liz Newhouse, Associate Director of the Texas Respite Resource Network, noted in her keynote address that respite care development has to become "coordinated, collaborative, and cooperative." The definition of those words, in the normal world of competing service systems and interests, is "an unnatural act committed by unconsenting adults."

And, when it comes to respite care, three other factors compound that historical lack of practice in cooperative, collaborative work in program development. One is the intensity of the need. Respite care is frequently cited as the "most needed," or "most valued" service, but the "least available." Second, there is simply not any promise of extensive new sources of public funding for respite programs in an era of social service cutbacks. While it is seen as "most important" by families, it is not usually seen that way by professionals. And third, "respite care" is simply still a foreign word or concept to most of the general public and policymakers, and even, indeed, to many families.

The purpose of this session and paper is to present and explore the results of several projects in Georgia in the past two years that move respite care development toward a "cooperative, collaborative, and coordinated" effort. You will hear presentations from three agencies that are working on different kinds of respite care development, a project funded by a grant from the Office of Human Development Services under the Temporary Child Care and Crisis Nurseries Act. That grant application came out of collaborative networking in a regional Metro Atlanta Respite Network. But these reflections on cooperative approaches are also based on work in one county (Cobb) in an inter-agency, interfaith respite care task force, and a state-wide project through the Governor's Council on Developmental Disabilities entitled "Partnerships in Respite Care." My particular purpose is to share some of the strategies used, but more importantly to focus on some principles that are evolving in our work on respite care, and some of the issues which impact effective networking and cooperative approaches. To outline, it will look at a background overview of respite care in Georgia, a summary of strategies and what's been done, and then articulate principles, directions, issues, and guidelines that are emerging from our work.

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Background: Respite Care in Georgia

In Georgia, at present, respite care is a service offered primarily by area-based developmental services (MH/MR/SA) programs. State standards outline possible types of respite care to include in-home respite, out-of-home respite, respite activities, respite care in group residences, and emergency respite care. The areas vary widely in amounts of funding used for respite care and in services offered. Services have been primarily for adults, with much of the respite taking place either in group homes or at institutions. Most areas have been limited by a lack of funds, a lack of providers, and difficulty in serving persons with multiple handicaps. It has been also limited to persons with mental retardation, with many fewer options for children who are chronically ill, emotionally disturbed, or who have other forms of developmental disabilities. (See Respite Survey, 1988, attached)

Some areas of the state have creative respite programs that have relied heavily on local initiative by parent organizations, e.g., a respite program in Savannah that receives county funding; a United Way funded ARC respite home in Douglasville, outside of Atlanta; and respite programs run by non-profit organizations in the metro Atlanta area who receive private, corporate, county, state, and, now, federal dollars, particularly Atlanta Respite Services and United Cerebral Palsy. The first publically funded respite home opened in Clayton County (south metro Atlanta) in the spring of 1990, with eight more projected for development, if funded, in the FY 91-95 improvement plans.

Six areas in Georgia have been funded as pilot family support program areas, and are in their third funding year. The program has been very popular with families, and the funds are frequently used for respite care, but that has not yet led to increased advocacy and legislative support for statewide expansion of the program.

In the mid-80's, the Governor's Council on Developmental Disabilities began to address respite care as one of its goals. A part-time consultant did a study of respite care in Georgia, which led to a report and a booklet on "Community Based Respite Care." A Respite Care Task Force was then initiated in 1987 to continue development. Initial goals of producing public education materials changed into a program staffed by a part-time consultant entitled "Partnerships in Respite Care." (See initial description, Attachments.) At the same time, that consultant, i.e., this author, was beginning in a part-time position in Cobb County as as a Chaplain/Consultant, with a primary goal of helping to initiate some new options for respite care for families. The initial goal was to work primarily with the development of respite care in the religious community. The potential for that kind of cooperative alliance is described more thoroughly in the paper, "Respite Care: The Call for Church/State Partnership." (Handout.)

II. Strategies

The efforts at networking and cooperative work in respite care have thus happened at three levels:

1. A county level, area program, in Cobb County.
2. In the metro Atlanta area, through the formation of a Metro Atlanta Respite Network
3. Statewide, through the Partnerships in Respite Care project of the D.D. Council. Through a survey, newsletter articles, presentations, technical assistance, consultations, and planning with the Respite Care Task Force for a recent state-wide conference on family support and respite care, a Georgia Respite Care Network has been formed. It is primarily a mailing list, but it is in the process of developing a new steering committee and directions "post-conference."

County Level Respite Care Task Force

At the county level, a cooperative partnership developed between Cobb Developmental Services and the Cobb ARC which led to formation of a Cobb Respite Care Task Force. That committee has involved parents, professionals (agency, school system, university, hospital), and clergy and/or lay leaders. Four goals were established: (1) Training teenagers to be special sitters, (2) Development of a respite referral pool, matching families to potential providers, funded by families, (3) assisting congregations to develop respite ministries, and (4) development of a respite home. Meetings have been every two months. The goals were too ambitious, but there has been varying degrees of success in training teenagers, development of the respite referral pool, and congregational ministries. A brochure has been the major public awareness tool. (Attachments)

Metro Area Respite Care Task Force

At the metro Atlanta level, an initial meeting of representatives from respite care programs, church groups, advocacy groups, and other interested persons led to a decision to form a Metro Atlanta Respite Network. Its Mission was as follows:

> The Metro Atlanta Respite Care Network is a coalition of agencies, individuals, organizations and congregations who are committed to the support and expansion of programs, services, and activities which provide temporary relief "respite care" for families who care for disabled or elderly family members on an ongoing basis.

Its Goals are:

1. Expand community awareness of the needs for respite care services for families caring for disabled or frail elderly family members.

2. Provide information and referral for persons seeking care services.

3. Work cooperatively to recruit and train respite care providers and volunteers.

4. Facilitiate the development of new respite care services and ministries by agencies, congregations, and other community organizations.

In the first "year," November 88-summer, 89, the Network tried to meet every month, and to form committees on training, referral, and congregational respite ministries. We tried to have the committees meet before a general meeting. It was too much to sustain. It did, however, provide the basis for cooperative work that enabled a quick, cooperative response to the Office of Human Services RFP in 1989 that led to the funding of the "Georgia Respite Project." The strength of the proposal was in the variety of respite options being funded and expanded: in-home respite care providers to new populations through the UCP program, center-based program for new clients through Atlanta Respite Services, and the recruitment and training of family day care providers to do respite care as well through Save the Children.

In the second year, summer 89-summer, 90, the Network has met for quarterly brown bag lunches, with presentations from different agencies or individuals, a chance to update people on programs and interests, and brainstorming, sharing of ideas, etc. My role as Coordinator has simply been to do the mailings, and to assist in arrangments and networking. The quarterly meetings have been well-attended and lively. Topics explored have included liability, presentations by two new programs (a day care center for medically fragile children and the new respite home in Clayton), summer recreational programs, and the Compeer program. Two efforts have developed with the Network that have not proceeded very far at present. One was a survey on cooperative training needs that was completed by UCP, which has led to their opening their training to any interested providers. The second is a Interfaith Task Force on Respite Care Ministries, which has developed a survey for use by religious groups, but which has not gotten off the ground. The one product developed has been a simple listing of respite services in the Metro Atlanta Area, which has been widely used.

State Respite Care Network

As stated above, a mailing list entitled the Georgia Respite Network has emerged from several projects, including the survey, articles in newsletters, and presentations at area and state-wide conferences and meetings. Through the D.D. Council, we have done periodic mailings of information about respite programs, resources, and issues to the mailing list. Technical assistance and resources have been provided to anyone who requests it. A goal has been to encourage and consult with local areas who want to initiate respite care planning and projects. One of the products that has emerged from that work is a series of guidelines for the development of a community based respite care task force.

And, finally, the statewide respite care task force initiated a planning meeting about a respite care conference which expanded into a family support conference. The Task Force expanded into the Planning Committee for the conference, one that eventually involved more than forty state-wide agencies and organizations. See attachments: "We Are Not Alone? Strengthening Families Through Community Partnerships." The agenda on the preconference institute was based input from the survey and a follow-up questionnaire. One hundred and twenty-five people attended the respite care conference, with over 300 at the following day on community partnerships. Feedback at the conference indicated great interest in an expanded Georgia Respite Network, more linkage between respite care for elderly persons and persons with developmental disabilities, and support for current goals we have for a state-wide directory of respite care programs, a listing of inexpensive, available resources, and development of a videotape for public education and awareness. One of my primary impressions at the conference was a real hunger for success stories, simple resources, and opportunities to share ideas and struggles.

The primary work since the conference with the statewide network has been to develop a second grant proposal that would provide funding to support sliding scale respite services to a number of areas around the state in smaller urban or rural areas. Those areas would have to organize community based task forces that would explore a variety of respite options while also developing and running the sliding scale respite services.

Enough Description!! How About Principles?

From our work in networking and developing cooperative approaches to respite care planning, a number of principles or planning guidelines are emerging, some of which are also articulated by others working in the area of respite care. They are:

A. Respite care is a community wide need, with community based resources available to meet those needs. It is a need for many kinds of caregivers, and thus crosses "disability" and "agency" lines. Respite care development calls for an interagency, networking approach to planning and development.

B. That kind of cooperative work is important because respite care is still a foreign term and word to the general public. Planning and education has to articulate that respite care is also a need for "typical" families, but is usually a taken-for-granted aspect of other kinds of community connections and services (e.g., schools, recreational programs, sitters, congregations, etc.)

C. Families and caregivers need to be involved in the planning and delivery of respite services. (Knoll and Bedford, Exceptional Parent, May/June, 1989) That may seem obvious, but it often does not happen. It is important for at least three reasons: (1) designing services that meet family needs, (2)developing trust by families in those services, and (3) motivating other community groups and resources to become, and stay, involved.

D. Families and caregivers need a variety of respite options open to them, for no one program fits all needs. Thus, a planning and development approach needs to explore and develop a "menu" of respite care options. They can range from informal networks to formalized services, e.g.

Neighbors and friends	Extended family
Congregation	Cooperatives
Day Care Providers	Sitters
In-home	Out-of home
Retreats/Vacations	Emergency
Volunteer	Paid
Recreation programs	Companionship

E. Most respite care likely happens through informal networks, and extended family and neighbors. Most families who do not have access to those networks, or who have not been able to utilize them for respite care, prefer for respite care to happen in ways that is most "typical" for other families with caregiving responsibilities. Thus, respite care planning and development needs to explore ways to tap the potential in natural networks while also developing more formal services. (Salisbury and Intagliata, 1986)

F. Respite services that are provided on a sliding scale basis need to take into account the expenses that a family may already be incurring in caregiving for a disabled child or member at home, but it is important that families participate in the expenses. If respite is a gift, it should be so by a volunteer respite network or program.

G. When communities organize to address a need, involving public, private, civic, and religious organizations, models emerge in a variety of ways that can be unique to that community. Planning should facilitate the development of community ownership of respite needs and a sense of community capacity to respond to those needs in a variety of ways. For example, resources and skills for training paid or unpaid respite providers are already available through agencies and families.

H. Respite care can be a product of may other kinds of programs and community involvments that enable families and children to be apart from one another. In fact, participation in other kinds of program is usually easier for families to request than respite care. One way of approaching respite care may thus be through the use of respite providers as "supported integration" coaches who facilitate participation by persons with disabilities in other community programs.

I. Respite care benefits everyone involved. It is not just for the caregivers, but also for the person with a disability who needs a respite from those caregivers, the caregivers (many of whom need the opportunity to give in that particular way), and the community as a whole, by facilitating community confidence and competence to respond to, and care with, families with disabled members.

J. Respite, recreation, and residential needs and programs are closely linked. The question of "Who watches?" in short run is closely tied to that same question in the long run. Without respite care beginning early and "typically," families don't have any practice in letting go, an experience that heightens that issue during periods when families need to be considering other residential options. Respite care planning needs to be very sensitive to the family issues of trust.

With those principles, respite care planning and development can potentially involve many facets of the community, many different kinds of agencies, organizations, advocacy groups, etc. A number of issues have arisen in trying to do that kind of cooperative planning, based on the above principles, that may serve as guidelines for others. They include:

A. Networking cannot be forced. Groups need to be involved out of their own self-interest, but also have to work hard together to look at the common ground. That is not easy for different advocacy groups in human services, who have been trained by experience to compete with others for funds and community attention.

B. That common ground is another crucial reason for the involvment of families, for it helps to keep others focused on the needs and tasks.

C. While advocating for a variety of respite options, it is also important to help something concrete to happen, even if it feels "small" at the beginning. In fact, "small" may be just the place to begin. It may be a directory, a brochure, a small program, or a particular story about one family and the mobilization of community resources around them to provide respite care. But it is important to do more than talk about respite care needs and options.

Conclusion: The Challenge to Professional Roles

Through the processes of building networks, coalitions, and community based task forces around respite care, in ways that attempt to involve and tap the potential of "generic" community resources, there is a paradoxical claim on the role of "service providers." On the one hand, the role shifts from providers to service to facilitators, trainers, and "guides" for the involvment by others in respite care. The danger is that we become an endless system of referral agents, albeit with wonderful theories about options, choice, and enabling generic resources. But for parents and families, the need is still there, and real, and the theories mean little:

Parable

I read how Quixote in his random ride
Came to a crossing once, and lest he lose
The purity of chance, would not decide

Whither to fare, but wished his horse to choose.
For glory lay wherever he might turn.
His head was light with pride, his horse's shoes

Were heavy, and he headed for the barn.

The other side of the paradox then calls us back to being providers of service, but not in the traditional way. For when professionals work closely with communities, in which they also live, recreate, worship, and work, the question may shift. The shift is from "How do they get respite?" or "Where?" to "How do we make it happen?" That may mean more personal involvment than we have traditionally been comfortable with. Yet, as we help to push the search for respite services back to ways that it can happen closest to family preferences, homes, and communities, it means we may indeed be part of the solution. The question may be that if it is good for other friends, networks, organizations, congregations, etc. to do, then it may also be good for mine.

Respite Care Survey: Initial Results. September, 1988

Returns included these results: 30

Geographical Areas: From program offices covering all counties except nine.

Types of Respite Programs Provided/Used In Your Area

Respite Homes	7
Developmental Training Home	23
State Institution	24
Volunteer	1
Church Based Program	2
Group Homes	20
Paid Public Providers	13
Private Agency	7
Parent Cooperative	1
Private/Non Profit	1
Family Support	1

Combination of sponsors 7 (at least)
Including:

In-home, residential and day center staff
Summer Camp (7)
Saturday Respite (2)
After School (4)
Recreation programs (2)
Project ARC, Albany
Corporate Grant (1)

Major Issues or Problems You See With Current Respite Programs in Your Area:

	#	%
Not enough funds	14	22
Not enough providers	8	13
Needs of clients with behavioral/medical problems	8	13
Problems with recruitment of providers	6	9
Over-regulation of respite homes, including lack of timely inspections.	4	6
Limited staff time to devote to respite development	4	6
Not enough homes	2	3
Not enough involvment from private, civic, church, United Way	2	3
Separation of local MR day services staff administratively from respite staff	2	3
Inadequate reimbursement for providers	2	3
Lack of state support for respite programs, i.e., state turning down federal grant monies for respite	1	1
Failure to recognize need for respite above age 6	1	1
Collection of fees	1	1
Lack of in home services	1	1
Reference checks for providers	1	1
Problems in rural areas	1	1
Limited options for families	1	1
Affordability	1	1
Lack of emergency respite	1	1
Lack of long-term respite	1	1
Total	61	

What respite needs are most difficult to meet, or are not being met?

	#	%
Clients with severe medical problems	13	25
Clients wtih severe behavioral problems	12	23
Multiply handicapped clients	7	13
Out of home respite for young clients with challenging behaviors	5	9
24 hr. care home	3	6
Lack of funds	3	6
Ongoing training for providers	2	4
Finding providers in rural areas	2	4
Reasonable cost	1	2
In-home providers	1	2
Community awareness of respite needs	1	2
Rate of pay for providers	1	2
Qualified providers	1	2
Total	52	

Would you be interested in a statewide respite network?

All yes.

Would you be interested in a state-wide conference on respite care?

29 yes, 1 maybe, 1 yes if "in south Georgia out of Atlanta."

Major issues the conference should address are:

How to identify and develop local support and ownership of respite programs	10
How to increase funding	6
How we are doing it now (models and handbooks)	4
Family support used for respite	3
Training Programs for respite providers	3
Programming for behavioral/medical clients	3
Recruitment	3
Setting up respite homes	2
How to prioritize respite needs	1
Utilizing non-group home, non-institutional care	1
Developing a variety of respite options	1
Liability issues	1
General management of respite programs	1

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